



**BILLING CODE 4165-15**

**DEPARTMENT OF HEALTH AND HUMAN SERVICES**

**Health Resources and Services Administration**

**Meeting of the Advisory Committee on Heritable Disorders in Newborns and Children**

**AGENCY:** Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS).

**ACTION:** Notice.

**SUMMARY:** The Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) has scheduled a public meeting. Information about the ACHDNC, a roster of members, the meeting agenda, as well as past meeting summaries is located on the ACHDNC website at <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>.

**DATES:** November 1, 2018, 10:30 a.m. - 5:30 p.m. ET and November 2, 2018, 9:00 a.m. - 3:00 p.m. ET.

**ADDRESSES:** This meeting will be held in person and by webinar. Advanced registration is required. Please register online at <http://www.achdncmeetings.org/> by 12:00 p.m. ET on October 29, 2018. The address for the meeting is 5600 Fishers Lane, Rockville, Maryland 20857.

**FOR FURTHER INFORMATION CONTACT:** Ann Ferrero, Maternal and Child Health Bureau (MCHB), HRSA, 5600 Fishers Lane, room 18N100C, Rockville, Maryland 20857; 301-443-3999; or [AFerrero@hrsa.gov](mailto:AFerrero@hrsa.gov).

**SUPPLEMENTARY INFORMATION:** The ACHDNC provides advice and recommendations to the Secretary of HHS (Secretary) on the development of newborn screening activities, technologies, policies, guidelines, and programs for effectively reducing morbidity and mortality in newborns and children having, or at risk for, heritable disorders. In addition, ACHDNC's recommendations regarding inclusion of additional conditions for screening,

following adoption by the Secretary, are evidence-informed preventive health services provided for in the comprehensive guidelines supported by HRSA through the Recommended Uniform Screening Panel (RUSP) pursuant to section 2713 of the Public Health Service Act (42 U.S.C. 300gg-13). Under this provision, non-grandfathered group health plans and health insurance issuers offering group or individual health insurance are required to provide insurance coverage without cost-sharing (a co-payment, co-insurance, or deductible) for preventive services for plan years (i.e., policy years) beginning on or after the date that is one year from the Secretary's adoption of the condition for screening.

During the November meeting, the ACHDNC will hear from experts in the field and discuss issues related to newborn screening information, education, training activities, and training resources. The ACHDNC will hear presentations on the use of genomic sequencing in newborn screening as well as the clinical setting for both well and sick infants. The ACHDNC will also discuss the nomination of cerebrotendinous xanthomatosis (CTX) to the RUSP and vote on whether to move the nomination forward to evidence review. Note that this vote is not on a proposed addition of a condition to the RUSP. Agenda items are subject to change as priorities dictate. Refer to the ACHDNC website for any updated information concerning the meeting.

Members of the public will have the opportunity to provide comments, which are part of the official Committee record. To submit written comments or request time for an oral comment at the meeting, please register online by 12:00 p.m. ET on October 26, 2018, at

<http://www.achdncmeetings.org>. Oral comments will be honored in the order they are requested and may be limited as time allows. Individuals associated with groups or who plan to provide comments on similar topics may be asked to combine their comments and present them through a single representative. No audiovisual presentations are permitted. Written comments should identify the individual's name, address, email, telephone number, professional or organization

affiliation, background or area of expertise (i.e., parent, family member, researcher, clinician, public health, etc.) and the topic/subject matter.

Individuals who plan to attend and need special assistance or another reasonable accommodation should notify Ann Ferrero at the address and phone number listed above at least 10 business days prior to the meeting. Since this meeting occurs in a federal government building, attendees must go through a security check to enter the building. Non-U.S. Citizens attendees planning to attend must notify HRSA of their planned attendance at least 10 business days prior to the meeting in order to facilitate their entry into the building. Contact Ann Ferrero using the information mentioned above by Thursday, October 18, 2018, 12:00 p.m. ET. All attendees are required to present government-issued identification prior to entry. The meeting will also be accessible via webcast. Instructions on how to access the meeting via webcast will be provided upon registration.

**Amy P. McNulty,**

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[FR Doc. 2018-20428 Filed: 9/19/2018 8:45 am; Publication Date: 9/20/2018]